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Brief Communication

Quality of life of caregivers and impact on the nuclear family of children with leukaemia in the National Cancer Institute of Sri Lanka

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Key words: childhood cancer, childhood leukaemia, caregiver, quality of life, nuclear family

Abstract

Childhood leukaemia is the commonest cancer in children aged below 15 years. A diagnosis of childhood leukaemia is a devastating experience for any parent. This hospital-based descriptive cross sectional study aimed to assess the quality of life (QOL) of caregivers and the impact on the nuclear families of children with leukaemia. A convenient sample of 140 caregivers was surveyed using an interviewer administered questionnaire. Nearly 50% of caregivers reported low QOL in the psychological 71(50.7%), social 66(47.1%) and environmental 64(45.7%) domains while most nuclear families underwent moderate financial 88(62.9%) and psychological 100(71.4%) impacts. There was a statistically significant decline in parental employment status following the diagnosis ($p<0.05$).

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Introduction

Leukaemia is the most prevalent cancer in children below the age of 15 years. Out of all cancer patients in the age group of 0-14 years in Sri Lanka, 44% of males and 37.9% females were suffering from leukaemia[1]. A diagnosis of childhood leukaemia is a devastating experience for any parent and it has been shown to inflict a significant negative impact on their quality of life[2]. This impact may well extend beyond the caregiver's personal confines to adversely affect the wellbeing of the nuclear family[3,4]. Shock, denial and disappointment in the initial stages of diagnosis and more long term feelings of depression and anxiety in caregivers and conflicts within the family due to role ambiguity and disordered interpersonal relationships have been reported[3,5]. Loss of employment, due to commitments of caregiving, while struggling to meet substantial treatment costs have increased the financial burden of illness on the family of children with chronic diseases including cancer[5].

Quality of life is a multidimensional indicator and therefore it is essential that all domains of quality of life of the caregivers, including physical, psychological, social and environmental aspects, need to be evaluated together with any financial and psychological impacts on the nuclear family. In Sri Lanka, no study has been conducted so far to assess the quality of life of caregivers and the impact on the nuclear family of children with leukaemia. Furthermore, there is minimal social support available for caregivers and their families during and after the treatment phase. Our study aimed to assess the quality of life of caregivers and the impact on the nuclear family of children with leukaemia. This study will address a critical knowledge gap

and provide the basis for planning any future community interventions aiming to improve the quality of life of caregivers of leukaemic children and effectively support their families.

Methods

A hospital-based cross sectional study was carried out in the National Cancer Institute of Sri Lanka, which is the leading hospital in the country dedicated to the diagnosis, management and follow-up of cancer patients island wide. A convenient sample of 140 caregivers of children aged up to 12 years who had received at least 3 months inward care or 6 months outpatient clinic follow up care for leukaemia were recruited over a period of 3 months. The caregivers of children who had been diagnosed with other chronic diseases such as asthma, cardiac conditions, diabetes mellitus or epilepsy were excluded.

Caregivers were interviewed at the hospital using three interviewer administered questionnaires. One was a Sinhala translation of a previously validated version of the World Health Organisation Quality of life Questionnaire (WHOQOL BREF). This is a shorter version of the original WHOQOL questionnaire and consists of 26 items measuring the broad domains of physical health, psychological health, social relationships and environment (including home environment, transport, financial resources, accessibility and quality of health and social care, participation in recreational and leisure activities etc)[6].Two other pretested questionnaires were used to collect information on the financial and psychological impact of the child's illness on the caregiver's nuclear family which included questions on caregiver's and other family member's employment status, psychological status and family income before and after the diagnosis of child's illness. Mean scores were calculated for each domain and the cut off for low, moderate and high were based on the standard deviations. The data were analyzed using descriptive statistics of the SPSS statistical package version 17.Ethics clearance was obtained from the Ethics Review Committee of the Faculty of Medical Sciences, University of Sri Jayewardenepura, Sri Lanka.

Results

Majority of the caregivers were mothers 122(87.1%) in the age group of 26-45 years (83.6%, n=117). Ninety four (67.1%) of the caregivers were educated up to Grade 11 in school, while another 29.3% (n=41) were educated up to Grade 13. In 38.6% (n=54) of the families, the affected child was the only child in the family (See Table 1 footnote). In the rest of the families, the siblings of the affected child were mainly looked after by the grandparents (n=50, 58.1%). Seventy two of the caregivers (51.4%) had to travel over 70km from their residence to reach the National Cancer Institute for their child's treatment while another 38 (27.1%) had to travel between 31–70km. Eighty seven (62.1%) of the caregivers reported that these visits to hospital incurred an average cost over Rs 500 per visit (Table 1).

The total score obtained for each domain of the WHOQOL – BREF questionnaire was categorized into low, moderate and high quality of life (QOL) for that specific domain (Table 2). The majority of caregivers reported a moderate physical QOL 70(50%), low psychological QOL 71(50.7%), low social QOL 66(47.1%) and low environmental QOL 64(45.7%). The total score obtained for the two questionnaires used to measure the financial impact and psychological impact on the nuclear family was categorized into severe, moderate and mild impact. The majority of nuclear families experienced moderate financial impact 88(62.8%) and moderate psychological impact 100(71.5%).

Table 1 : Characteristics of the caregivers and factors related to child's treatment

Characteristic	N (%) N=140
Age (years)	
<=25	13 (9.3)
26 – 35	70 (50.0)
36 – 45	47 (33.6)
46 – 55	10 (7.1)
Relationship to the patient	
Mother	122 (87.1)
Father	18 (12.9)
Highest level of education	
Up to Ordinary level (Grade 11)	94 (67.1)
Advanced level (Grade 12-13)	41 (29.3)
Tertiary education	4 (2.9)
Never attended school	1 (0.7)
Caregiver of the siblings[1]	
A parent	25(29.1)
Grandparents	50 (58.1)
Other relatives	11 (12.8)
Distance to hospital from home (km)	
<=5	9 (6.4)
6 – 30	21 (15.0)
31- 70	38 (27.2)
>71	72 (51.4)
Average time taken to travel from hospital to home (hours)	
< 1	34 (24.3)
1 – 2	42 (30.0)
2 - 4	48 (34.3)
>= 4	16 (11.4)
Total cost per hospital visit (in Sri Lankan Rupees)	
< 100	14 (10.0)
101 – 500	39 (27.9)
501 – 1000	58 (41.4)
>1000	29 (20.7)
Time since diagnosis	
<=6 months	34 (24.3)
7 months – 1 year	43 (30.7)
1-2 years	41 (29.3)
2-4 years	19 (13.6)
4 – 6 years	3 (2.1)
Parental employment status before diagnosis	
Single parent employed	107(76.4)
Both parents employed	33 (23.6)
Parental employment status after diagnosis	
Single parent employed	128(91.4)
Both parents employed	12 (8.6)

[1]n=86 as only 86 (61.4%) of the children had siblings

Table 2: The quality of life (QOL) of caregivers in different domains and impact on nuclear family (N=140)

Quality of life domain and impact on nuclear family	Low N (%)	Moderate N (%)	High N (%)
Quality of life			
Physical QOL	36 (25.7)	70 (50.0)	34 (24.3)
Psychological QOL	71 (50.7)	45 (32.2)	24 (17.1)
Social QOL	66 (47.1)	50 (35.7)	24 (17.1)
Environmental QOL	64 (45.7)	62 (44.3)	14 (10.0)
Impact on nuclear family			
Financial impact	27 (19.3)	88 (62.8)	25 (17.9)
Psychological impact	24 (17.1)	100(71.5)	16 (11.4)

Chi square analysis revealed a statistically significant decline in the environmental QOL of the caregiver with increasing length of time since the diagnosis of child's illness(χ^2=16.9, p<0.05) Furthermore, there was a statistically significant decline in the parental employment status (the number of parents employed) after the diagnosis of their child's illness (χ^2=44.3, p<0.05).

Discussion

Our study revealed that caregivers of leukaemic children had impaired physical, social, psychological and environmental QOL. To our knowledge, there have been no recent studies reporting the physical and environmental QOL specifically in caregivers of leukaemic children, however, there is comparable evidence in relation to caregivers of children with cancer in general[7].

In our study, 71(50.7%) caregivers had a low psychological QOL while another 45(32.2%) had a moderate psychological QOL. This is consistent with previous evidence where mothers of children with leukaemia reported a higher risk of poor mental health and depression compared to mothers of children without leukaemia[2,4,8].

Furthermore, Yamazaki et al reported that these mothers also had low QOL in relation to their social functioning[2]. Similarly, our study revealed that nearly 50% of the caregivers had low social QOL. As the domain of social QOL in the WHOQOL questionnaire includes the facet of personal and family relationships, this may reflect that the caregivers in our study may have impaired relationships. Pai et al reported similar findings where the caregivers of childhood cancer patients reported higher levels of family conflict[3] while a qualitative study by Tarr & Pickler noted that stronger marital relationships tend to contribute positively towards better coping strategies as a caregiver[9].

This study found that a low environmental QOL, which includes opportunities for leisure activities, was significantly associated with length of time since the diagnosis of the child's illness indicating that the ability of caregivers to engage in these pursuits had been affected. Interestingly, previous evidence reports that the psychosocial QOL of caregivers of children with cancer tends to improve over time[7], although we failed to demonstrate such an association in our sample of caregivers.

In line with previous evidence[10], our study also noted a statistically significant difference in parental employment status before and after the diagnosis of their child's illness with more caregivers losing their jobs. This occurrence may again be attributed to obligations of care giving. This highlights the need for more organised social support during this challenging time period.

In conclusion, this study provides important Sri Lankan evidence on the substantial negative impact of illness on the nuclear families of children with leukaemia and on the quality of life of their caregivers. It provides useful preliminary evidence on which future research could build, to better identify the physical and psychosocial needs of this highly vulnerable population in order to design and implement cost effective and culturally sensitive interventions to provide psychosocial support.

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